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Influential Factors Contributing To Compliance And/Or Non-Compliance With The Gluten-Free Diet For Celiac Disease Individuals

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Influential Factors Contributing to Compliance and/or Non-Compliance with the Gluten-Free Diet for Celiac Disease Individuals

(TITLE)

BY

Jill Barnes

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Abstract

Objective: The purpose of this study was to determine the influential factors of compliance and/or non-compliance with the gluten-free diet (GFD) for celiac disease (CD) individuals.

Methods: The data collection instrument was a self-developed survey using kwiksurveys.com. The data were collected via online survey distribution to CD support group facilitators in nine Midwestern states. CD support group facilitators assisted snowball sampling by distributing the online survey to other members of the support groups. Qualitative data from survey question 12 was reviewed for themes and patterns and discussed in a narrative form. Statistical analysis of the data was done using SPSS software to determine the influential factors that predict compliance and/or non-compliance with the GFD.

Results: Of the 146 participants, 129 (88.4%) were female and 17 (11.6%) were male (5-78 years old). Participants had a mean age at diagnosis of CD of 39 ± 17 years. The current study was unable to accept any of the research hypotheses; however, the data found that 24.0% of the variance in compliance with the GFD can be determined when knowing the subject's age at diagnosis, current knowledge of the GFD, influence of social pressures and situations, and availability of GF foods. The common challenges and strategies presented by the participants in question 12 support the findings of the study.

Conclusions: Compliance rates with the GFD for CD individuals could be increased with knowledge of the individual's age at diagnosis, knowledge of the GFD, influence of social pressures and situations, and availability of GF foods 24.0% of the time.

Understanding these and other factors that contribute to compliance rates is important for health care practitioners in order to improve educational strategies for effective treatment of CD using the GFD.

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Chapter 1

INTRODUCTION

The prevalence of Celiac Disease (CD) has grown drastically in the past few decades. It has changed from a rare condition to a commonplace disease in a relatively short amount of time. Today, "CD affects 1 in 133 Americans" (Fasano et al., 2003), corresponding to about three million Americans that have the CD genotype. If left undiagnosed or untreated, CD can have multiple severe complications on the individual's health such as short stature, osteoporosis, infertility, neurological disorders, and many others. Currently, following a gluten-free diet (GFD) is the primary treatment for CD. Strict adherence to a GFD is challenging and is a life-long lifestyle change for individuals diagnosed with the disease. In an effort to improve education strategies for effective treatment of CD using the GFD, understanding compliance rates with the GFD for CD individuals is desired.

Purpose of Study

The purpose of this research project was to determine the influential factors of compliance and/or non-compliance with the GFD for CD individuals.

Research Questions

The research questions included:

1. Does age of diagnosis significantly predict compliance and/or non-compliance with the GFD?
2. Does knowledge of the GFD significantly predict compliance and/or non-compliance with the GFD?

3. Does the availability of gluten-free (GF) food significantly predict compliance and/or non-compliance with the GFD?
4. Do social pressures and situations significantly predict compliance and/or non-compliance with the GFD?
5. Does the severity of physical symptoms of CD significantly predict compliance and/or non-compliance with the GFD?
6. Does the cost of GF foods significantly predict compliance and/or non-compliance with the GFD?

Research Hypotheses

Hypotheses of this research project included:

1. Early diagnosis of CD will predict significantly ($p \leq 0.05$) improved compliance with the GFD.
2. Increased knowledge of the GFD will predict significantly ($p \leq 0.05$) improved compliance with the GFD.
3. Availability of GF foods will predict significantly ($p \leq 0.05$) improved compliance with the GFD.
4. Social situations will increase pressure which will predict significantly ($p \leq 0.05$) decreased compliance with the GFD.
5. Severe physical symptoms of CD will predict significantly ($p \leq 0.05$) increased compliance with the GFD.
6. The high cost of GF foods will predict significantly ($p \leq 0.05$) decreased compliance with the GFD.

Significance of the Study

This study is significant and will contribute to the current body of research by providing health care practitioners with a better understanding of compliance rates with the GFD for CD individuals. The information may be used to better understand education techniques for dietary instruction. Participants will contribute to the understanding of CD and the challenges individuals face with the GFD.

Limitations of the Study

This study was limited to individual's self-reported diagnosis of CD and did not attempt to clinically diagnosis CD among participants. This study was also limited by individual's self-rating of knowledge of the GFD and did not attempt to test the individual's knowledge of the GFD. Due to electronic distribution of the data collection instrument, the study was limited to those who have access to a computer with an internet connection. This study was limited to members of CD support groups, and may induce bias from participants already actively perusing techniques for overcoming challenges associated with the GFD.

Definition of Terms

Below are the terms that were defined for clarity of the research:

1. Compliance is the act of conforming to the guidelines; an act of following a prescribed treatment.
2. The Gluten-Free Diet (GFD) is the sum of foods consumed by an individual that are free from ingredients derived from gluten containing products such as wheat, barley, or rye.
3. Non-compliance is the act of not following a prescribed treatment.

Chapter 2

REVIEW OF LITERATURE

According to Zwloinska-Wcislo and colleagues, CD is a "chronic inflammatory disease of the gastrointestinal (GI) tract of autoimmune etiology in genetically predisposed individuals" (Zwloinska-Wcislo, Galicka-Latala, Rudnicka-Sosin, & Rozpondek, 2009, p. 370). The Meir Medical Center in Israel defines CD as a prevalent, genetically determined, autoimmune, chronic inflammatory state caused by intolerance of gluten that results mainly in GI manifestation (Nemet, Raz, Zifman, Morag, & Eliakim, 2009). The American Dietetic Association (ADA) agrees that CD is an autoimmune reaction to the protein gluten causing damage to the small intestine in patients with the genetic condition (American Dietetic Association [ADA], 2009). The Mayo Clinic of Rochester, Minnesota, states the same conclusions that CD is a digestive disease triggered by the consumption of the protein gluten causing damage to the GI tract (Mayo Foundation for Medical Education and Research [MFMER], 2008). Worldwide, CD is defined through research as a genetic autoimmune disorder with symptoms brought on by the consumption of the protein gluten. Multiple researchers agree and the definition of CD used in practice is uniform worldwide (Blaska, 2007; McGowan, Castiglione, & Butzner, 2009; & Darewicz, Dziuba, & Minkiewicz, 2008).

Description of Celiac Disease (CD)

The protein gluten is comprised of the storage proteins of wheat (Schuppan, Dennis, & Kelly, 2005). The components of the storage proteins are called ethanol-insoluble glutenins and alcohol-soluble gliadins (Schuppan et al., 2005 & Shan & Khosla, 2007). The ethanol-insoluble glutenins are the structures commonly thought of in baking

("Getting out the Gluten", 2009). Gluten, from the Latin word for glue, is responsible for making the dough resilient and stretchy allowing for baked goods to hold their desired structure ("Getting out the Gluten", 2009). Wheat variants like rye and barley produce similar gliadins and glutenins, contain a high percentage of the amino acids glutamine and proline, and form similar complex molecular structures (Schuppan et al., 2005 & "Celiac Disease: Gluten Sensitivity Enteropathy", 2007). Molecular components of oats and rice differ and are believed to not be associated with the inflammatory response. Research conducted by Dr. Schuppan focuses on a part of the gliadin peptide in wheat called the alpha-gliadin as the causative agent in the pro-inflammatory response in human studies (Schuppan et al., 2005). This alpha-gliadin component cannot be broken down by digestive enzymes. In rye, the structure that cannot be broken down is called secalin and in barley it is called hordein ("Getting out the Gluten", 2009).

When these proteins are absorbed into the walls of the small intestine by celiac patients, the immune system misreads the signal and sees the proteins as invaders instead of nutrients ("Getting out the Gluten", 2009 & Kaukinen, Collin, Laurila, Kaartinen, Partanen, & Maki, 2007). The immune system releases an inflammatory response that causes damage to the tissues ("Getting out the Gluten", 2009). The damage can be extensive to the villi of the small intestine causing them to lose their shape and ability to produce digestive enzymes. The loss of the digestive enzymes makes it difficult for the surrounding villi to absorb other nutrients the body needs ("Getting out the Gluten", 2009).

Currently, the best and most common treatment for CD is strict adherence to a GFD (Neiwinski, 2008). It is important that dietitians, who play a critical role in the

management of CD, be up-to-date with the current teachings of a GFD (Shepherd & Gibson, 2006). Avoiding gluten containing products like wheat, barley, and rye is essential to the GFD (Amerine, 2006). Due to varying symptoms among CD patients, the amount of tolerable gluten is wide-ranging (Akobeng & Thomas, 2008). A study conducted by Akobeng and Thomas tried to find a tolerable threshold for gluten among CD patients. Some patients tolerated 34-36 mg of gluten per day while others developed intestinal damage form only 10 mg of gluten per day. There is not a common tolerable threshold for all CD patients, and as a result, dietary changes are strictly individualized (Akobeng & Thomas, 2008).

Dr. Schuppan recognizes the difficulties this presents to CD patients and discusses a few of the alternative treatments currently being studied (Schuppan et al., 2005). Pharmaceutical companies are looking for drug treatments that would block the absorption of gluten ("Getting out the Gluten", 2009 & Baldassarre, Laneve, Grosso, & Laforgia, 2008). The treatment is progressive and if successful, may provide a guide for the research and treatment of other autoimmune diseases, but Food and Drug Administration (FDA) approval has not been received. The current standard for the management of CD is the elimination of gluten from the diet.

The National Institute of Health (NIH) recommends that CD patients avoid foods containing wheat (wheat germ, flour/wheat starch, etc), barley, and rye (National Institute of Health [NIH], 2007). It is important to follow this diet in order to control symptoms, heal damage to the intestines, and prevent any further damage to the GI tract (McCreery, 1976). The NIH says after beginning on a GFD, symptoms will start to decrease within days (NIH, 2007). After about two weeks of a truly GFD, patients report significantly

diminished symptoms and delayed gastric emptying returning to normal (Mason, 2009 & Perri, Pastore, Zicolella, Annese, Quitadamo, & Andriulli, 2000). The small intestine will heal in 3 to 6 months for children and potentially years for an adult (NIH, 2007). Once the intestine is healed, the villi will be able to properly absorb nutrients into the bloodstream (NIH, 2007). The ADA says that adherence to the GFD is a life-long lifestyle change necessary for management of CD in order to maintain nutrient absorption and avoid nutrient deficiencies (ADA, 2009). Following a GFD means removing any food product containing wheat, rye, or barley (NIH, 2007 & "Living Without Gluten", 2009) such as grains, pastas, and cereals. CD patients can replace these foods in their diet with similar products that are gluten free; potato, rice, soy, amaranth, quinoa, buckwheat, or bean flour are gluten free (NIH, 2007). Vitamin and mineral supplements may need to be taken due to atrophy and malabsorption in the upper part of the small intestine ("Important Supplements for Gluten-Free Living", 2009). As the small intestine heals with compliance to the GFD, vitamin and mineral supplements can be adjusted to reflect individual needs ("Important Supplements for Gluten-Free Living", 2009).

Adding oats to a GFD is controversial. In the past it was thought to be unsafe, but current findings say it may be acceptable to add oats to a GFD (Leeds, Hopper, & Sanders, 2008). "Theoretically, oats should be tolerable; however, oats are traditionally contaminated with wheat flour during milling which brings up safety concerns for CD patients" (Leeds et al., 2008, p. 158). One study published by British Medical Bulletin tried the reintroduction of oats to CD patients only after their symptoms had resolved and antibodies became negative. If the CD patient experienced a return of symptoms after consuming a non-contaminated oat source, the patient was thought to be intolerant of oats

as well as having CD (Leeds et al., 2008). Another study conducted over a 12-month period in Finland using 32 adult patients (19 female, 13 male) found that using oats as a part of a GFD in the treatment of CD is safe in both short and long term utilization (Kemppainen, Heikkinen, Ristikankare, Kosma, Sontag-Strohm, & Brinck, 2008). The study followed the subjects with a daily intake of 100 grams of oats for 12 months. The subjects were split into two groups at random with one group using regular oats and the other group using unkilned oats. After 6 months, the groups switched so the group using regular oats were now using unkilned oats and vice versa. After the 12 months, the study found no significant changes in the duodenal biopsies, in the levels of endomysial antibodies or in the well-being of the patients. Thus, large amounts of oats in either kilned or unkilned form pose no real threat to adult CD patients and can be viewed as safe to add to a GFD (Kemppainen et al., 2008).

A third study conducted in 2008 in Norway found that most adult CD patients can tolerate oats as a part of a GFD (Guttormsen, Lovik, Bye, Bratlie, Morkrid, & Lundin, 2008). The study collected serum from 136 patients with controlled CD and 139 controls to evaluate elevated IgA antibodies to oat prolamins. The study found that both oat-eating and non-oat-eating CD patients had elevated IgA levels to wheat, oats, and tissue transglutaminase compared to healthy controls. The study concluded that oats do not contribute to increased levels of IgA in adult CD patients and can be tolerated on a GFD. These research results provide evidence that oats are a safe substitute for wheat and wheat products in a GFD. Like all things in nutrition, adding oat grain to the GFD should be evaluated on case by case bases, but it does not seem to be related to the intestinal inflammatory response of CD (Guttormsen et al., 2008).

Consequences of Undiagnosed/Untreated CD

There are multiple complications that could arise due to undiagnosed or untreated CD. Children with undiagnosed or untreated CD may not reach their full height potential resulting in short stature as an adult (Tau, Mautalen, De Rosa, Roca, & Valenzuela, 2006). Adults with undiagnosed or untreated CD may experience bone loss and the development of osteoporosis (Sategna-Guidetti, Grosso, Grosso, Mengozzi, Aimo, & Zaccaria, 2000). Both women and men affected by CD may experience a degree of infertility if left undiagnosed or untreated (NIH, 2007), and neurological disorders may arise with the progression of CD (Martin, Romito, Pepe, De Vivo, Merola, & Limatola, 2006).

Short Stature and CD

Undiagnosed or untreated CD has been linked to multiple nutrient deficiencies and autoimmune disorders resulting in complications such as short stature (Radlovic, Mladenovic, & Lekovic, 2009). Short stature may be a common presentation of CD for children as illustrated by a study conducted in India by Bhadada and colleagues (Bhadada, Bhansali, Kochhar, Menon, Sinha, & Dutta, 2008). The study involved 176 children and followed their growth for a two year period. All the children were considered to have short stature at the beginning of the study. Screenings and tests were performed to diagnose the etiology of their short stature. The study found that 15.3% of the children with short stature also had CD making it the single most common cause. The measured growth rate of the 15.3% was 2.9 +/- 0.49 cm/year with untreated CD. Once a GFD was administered the growth rate of those with CD increased to 8.9 +/- 2.2 cm/year during the follow up period of six to nine months (Bhadada et al., 2008). The

increase in growth rate after the initiation of the GFD, seen in this study in India and other studies, indicates that short stature may be due to malnutrition caused by CD (Radlovic et al., 2009).

The study in India proposes three mechanisms for the cause of short stature in CD patients; the first is malabsorption induced malnutrition (Bhadada et al., 2008). CD can cause protein energy malnutrition as well as vitamin D and calcium malabsorption (Bhadada et al., 2008). Calcium and vitamin D contribute to bone growth and health and without proper amounts of these nutrients bone may not reach maximum density and growth ("Osteoporosis and Digestive Disorders", 2008). The second cause may be attributed to a growth hormone resistance seen by the elevated growth hormone levels and the low circulating insulin levels in the children (Bhadada et al., 2008). Growth hormone and circulating insulin are responsible for growth from early childhood to puberty (Bhadada et al., 2008). Poor nutrition status due to malabsorption can influence the production of insulin and hinder growth rate in children (Ingegnosi, Caruso-Nicoletti, D'Amato, D'Annunzio, & Lorini, 2008). The third cause outlined by the study is hypogonadism, which attributes to low gonadotrophins and low testosterone also delaying peak bone mass and inhibiting pubertal growth spurts (Bhadada et al., 2008).

Giovenale and colleagues conducted a study in 2006 which tested 7066 children (2-14 yrs) for growth hormone deficiency (GHD) and CD (Giovenale, Meazza, Cardinale, Sposito, Mastrangelo, & Messini, 2006). Of those tested, 650 had GHD and 44 had CD. The association between the two conditions was found in only 16 children making up 0.23%. Those 16 children did not grow for 1 year while on a GFD and thus GH treatment was started to initiate growth. The data were not overly significant and so

the conclusion was to have children with CD showing no catch-up growth after administration of a GFD to be screened for GH deficiency (Giovenale et al., 2006).

A study in Italy looked at 1066 children with short stature and found 210 (19.7%) had GHD and 12 had CD (Bozzola, Giovenale, Bozzola, Meazza, Martinetti, & Tinelli, 2005). After the 12 CD children were put on a GFD for one year, nine showed a positive effect on growth rate. This study also indicates children with CD should be screened for GHD if growth rate does not improve with a GFD after an appropriate amount of time (Bozzola et al., 2005).

The studies mentioned show CDs relation to short stature may be primarily attributed to malabsorption and possibly linked to GHD (Bhadada et al., 2008; Giovenale et al., 2006; & Bozzola et al., 2005). In most cases, the children in these studies improved their growth rate after a GFD was administered and intestinal damage was repaired enabling increased absorption of nutrients like calcium and vitamin D. With proper nutritional status, bone will have the nutrients it needs to reach full growth potential (Radlovic et al., 2009).

Osteoporosis and CD

Around 30% of newly diagnosed CD patients have a degree of bone loss (Mangione, 2008). If that bone loss is left untreated, osteoporosis has an increased chance of development (Mangione, 2008). Research in past years indicates that CD patients have a lower bone mineral density, which is a risk factor for fractures (Ludvigsson, Michaelsson, Ekbom, & Montgomery, 2007). A study was conducted in Sweden to assess the association between CD and bone fractures (Ludvigsson et al., 2007). They followed 65,000 individuals from 1964 to 2003, and 13,000 with CD in the

same time period. At the end of the study, they calculated a hazard ratio for the groups and found that CD had significant influence on hip and other fractures after CD diagnosis (Ludvigsson et al., 2007).

A study in 2001 followed 255 women (all showing signs of osteoporosis), to understand the prevalence of CD in osteoporotic women (Nuti, Martini, Valenti, Giovani, Salvadori & Avanzati, 2001). After the first CD screening, 53 women tested positive for CD. Bone metabolism was then evaluated with a series of tests and found that 24 women with CD antibodies had a significant reduction in serum calcium along with other blood chemistry signs of decreased bone metabolism. The study concluded that undiagnosed CD can increase calcium malabsorption, cause an unavailability of vitamin D, and result in marked bone loss (Nuti et al., 2001).

Reduced bone mineral density is often seen in untreated CD patients as a result of malabsorption (Capriles, Martini, & Areas, 2009). It could also be associated with pro-inflammatory cytokines or a misbalanced bone remodeling. A study in 2009 in Brazil suggested chronic inflammation found in untreated CD may increase production of cytokines, increasing bone resorption and bone loss. The study concludes that a GFD can help increase bone mineral density in children and help reduce the risk for development of osteoporosis later. Capriles says this method works well for children but significant increases in bone mineral density were not seen for adult CD patients on a GFD (Capriles et al., 2009).

Agardh conducted a study in Sweden in 2009 that looked at the association between the serum markers (CD antibodies) and decreased bone mass and the incidence of fractures in middle-aged women (Agardh, Bjrck, & Agardh, 2009). A total of 6480

women filled out surveys, had x-rays, and underwent blood tests to evaluate the correlation. The results showed a connection between those women who had high levels of the CD antibody and a decrease in bone mass. These 59 women (ages 50 to 64) had a higher prevalence of osteoporosis and an increased frequency of fracture (Agardh et al., 2009).

These studies illustrate an association between osteoporosis and CD and bring up the questions of the mechanism behind the connection. The mechanism is explained by Zofkov in a study conducted in 2009. Zofkov (2009) explains that over production of certain cytokines can increase bone resorption, which is also increased by hyperparathyroidism connected with malabsorption of calcium and vitamin D (Zofkov, 2009). The interaction of these mechanisms can cause a loss in bone mass. Zofkov and other researchers recommend calcium metabolism and bone mass screenings for CD patients (Zofkov, 2009 & Kavuncu, Dundar, Ciftci, Evcik, & Yigit, 2009).

Infertility and CD

CD may have a role in infertility for some patients, even if GI symptoms are not present (Seungdamrong & McGovern, 2007). An estimated one in 80 pregnancies may be affected by CD, and if untreated may result in miscarriage, intrauterine growth resistance (IUGR), or stillbirth (Anjum, Baker, Robinson, & Aplin, 2009). Malabsorption induced malnutrition may be one factor contributing to the negative pregnancy outcomes. The inappropriate production of cytokines in the GI tract causes atrophy of the villi that may inhibit vitamin and mineral absorption important for pregnancy (Seungdamrong & McGovern, 2007). Studies have shown that increased folic acid intake during pregnancy reduces the risk of neural tube defects in offspring

(Wolff, Witkop, Miller, & Syed, 2009). For CD patients, folic acid absorption can be affected by villeous atrophy and inadequate amounts of folic acid may contribute to low birth weight, preterm birth, and birth defects (Seungdamrong & McGovern, 2007). Low folic acid levels may also contribute to increased homocysteine levels, which is a risk factor for recurrent miscarriages (Haines, Anderson, & Gibson, 2008). Adequate iron status during pregnancy is shown to aid in early brain development, tissue oxygenation and energy metabolism, and neurodevelopment (Rioux, Lindmark, & Hernell, 2006). Malabsorption of iron during pregnancy due to CD may cause delayed brain development, neurological conditions, and impaired functional status of the infant (Seungdamrong & McGovern, 2007). Inadequate B complex vitamins during pregnancy may attribute to failure to thrive, developmental delays, and megaloblastic anemia in infants (Zengin, Sarper, & Caki Kil, 2009). Lack of absorption of B complex vitamins in CD patients during pregnancy may result with the same consequences (Seungdamrong & McGovern, 2007).

Placenta function may be compromised during pregnancy for CD women causing IUGR. IUGR has a nine-fold increased incidence in CD women and may increase morbidity and mortality during pregnancy (Anjum et al., 2009). A study looking at the function of autoimmune immunoglobulin A (IgA) found that IgA from the mother became associated with antigens at the syncytial surface of the placenta which inhibited tissue transglutaminase (TGases) function. Tgase plays a role in trophoblast apoptosis and if inhibited causes the placenta to carry a high volume of IgA which may lead to developmental or functional impairment for the embryo (Anjum et al., 2009).

Both women and men have reported infertility in association with CD (NIH, 2007). Women report increased infertility, recurrent spontaneous abortions, and preterm delivery and men report reduced fertility and sexual dysfunction related to CD. The mechanisms discusses above present some correlation between infertility and CD however no conclusive evidence has been reported. Further research is needed to determine the actual incidence of infertility among CD individuals (NIH, 2007).

Neurological Disorders and CD

In recent decades, neurological conditions have been reported in some CD patients (Freeman, 2008 & Grossman, 2008). For some, the discovery of these neurological conditions may be the initial presentation of CD and lead to its diagnosis (Freeman, 2008). While in others, the neurological conditions may have been brought on by malabsorption due to CD (Freeman, 2008; Niemer, 2007; & Hu, Murray, & Greenaway, 2006). Depending on the degree of atrophy in the small intestine, conditions like Wernicke-Korsakoff syndrome and Beri-beri may develop due to malabsorption of vitamins (Freeman, 2008). Some studies suggest a GFD may have a positive effect on neurological symptoms while others show a continual progression of the condition. Further research is needed to determine the effectiveness of adhering to a GFD on neurological conditions (Freeman, 2008).

The autoimmune mechanism responsible for the development of neurological conditions in CD patients is unknown but one study hypothesized that a hormonal immune mechanism is involved (Briani, Zara, & Alaedini, 2008). In this study, 71 CD patients were assessed for neurological conditions by screening serum antibodies to neural antibodies. Neurological conditions like headache, depression, entrapment

syndromes, peripheral neuropathy, and epilepsy were found in 22.5% of CD patients tested. Follow up of the 22.5% did not show any changes in serum antibodies regardless of diet. This study suggests a GFD does not provide positive effects on neurological condition development (Briani et al., 2008).

Another study at Cornell University suggests the hormonal immune mechanism of molecular mimicry between gliadin and nervous system proteins (Alaedini, Okamoto, & Briani, 2007). They looked at cross-reactivity of animal and human anti-gliadins Abs and nervous system Ags. The cross-reactivity of rabbits to synapsin I, a group of neuronal phosphoporteins involved in regulation of neurotransmitter release, was strong. In humans with CD, the anti-synapsin Ab reactivity was also strong in contrast to the absence of anti-synapsin Ab reactivity in control subjects. This suggests CD may contribute to increased anti-synapsin Ab reactivity and the development of neurological conditions (Alaedini et al., 2007).

Other studies discuss the mechanism of Tgases in CD individuals and the development of neurological disorders (Tau et al., 2006; De Vivo & Gentile, 2008; & Gentile & Cooper, 2004). Tgases are a family of enzymes that catalyze cross-linking reactions in the body for important functions like blood clothing, hair follicle differentiation, assembly and remodeling of the extracellular matrixes, cell signaling and apoptosis (Tau et al., 2006; Wodzinska, 2005; & Sblattero, Glorian, Azzoni, Zyla, Park, & Baldas, 2002). Tgases may contribute to atrophy in the small intestine by premature cell apoptosis and matrix degeneration of the villi. Truncated villi are responsible for malabsorption and may contribute to neurological conditions (De Vivo & Gentile, 2008). Further research is needed to determine if increased levels of Tgases are a causative

factor in neurological disorder development; however one study found Tgases may create antigenic determinants for the production of autoantibodies in CD (Wodzinska, 2005). Increased neurological autoantibodies in body tissues may increase nerve cell apoptosis and the development of Alzheimer's, Huntington's, Parkinson's, and other neurodegenerative diseases (Niemer, 2007; Wodzinska, 2005; & Zelnik, Pacht, Obeid, & Lerner, 2004).

Progressive research in new therapeutic treatments for neurodegenerative diseases focuses on Tgase inhibition (Gentile & Cooper, 2004 & Wodzinska, 2005). One study using mice showed an increase in lifespan when Tgase 2 was knocked out (Gentile & Cooper, 2004). Cystamine, an in vitro Tgase inhibitor, was able to be converted to the potent antioxidant cysteamine in vivo potentially alleviating oxidative stress on affected mice brains (Gentile & Cooper, 2004). This study is not conclusive; however it has made Tgase activity a target for therapeutic research to discover inhibitors of Tgase enzymes (Gentile & Cooper, 2004; Wodzinska, 2005; & Poloni, Vender, & Bolla, 2009).

Treatment using GFD/Potential Factors Influencing Compliance

Currently, the best and most common treatment of CD is strict adherence with the GFD. However, not all individuals diagnosed with CD are successful at following the GFD as closely as necessary for proper recovery from and prevention of symptoms. Research outlines potential factors that influence individuals diagnosed with CD to either comply with the GFD or to not comply with the GFD.

Financial Restraint

The GFD can be considered an expensive diet as determined by Lee and colleagues in a study conducted in 2007. The study compared 11 products (regular wheat-based and their gluten free counterparts) to evaluate the economic burden of adhering to a GFD (Lee, Ng, Zivin, & Green, 2007). After assessing "specific brand, weight, package size, venue, and geographic location within the United States" (Lee et al., 2007, p. 424), the study concluded that GF foods are considerably more expensive than regular, gluten-containing foods and are not as readily available. This study suggests that the financial burden of GF foods may impact compliance with the GFD for CD individuals (Lee et al., 2007). More research and evidence is needed in this area to draw more concrete conclusions.

Social Pressures

Social situations present pressure for CD individuals to comply or not comply with the GFD. A study by Olsson and colleagues looked at adolescents with CD and sought to determine why adolescents comply, occasionally comply, or do not comply with the GFD (Olsson, Hornell, Ivarsson, & Sydner, 2008). The study assessed 47 CD adolescents (ages 15-17 years old), broken down into 10 focus groups, and their everyday social settings in relation to compliance or non-compliance with the GFD. After analysis of the focus group interviews, the majority of adolescents agreed that being at home was the easiest place to comply with the GFD and eating out with friends or at school was the most difficult place to comply with the GFD. "The attitudes and behaviors of significant others (teachers, friends, etc) affected the decision to comply or not in different social situations" (Olsson et al., 2008, p. 362). Feelings of embarrassment fueled non-

compliance as well as not wanting to be a burden to anyone else. The study concluded that compliance with the GFD was complex and was influenced by "limited knowledge, poor availability, low sensory acceptance, inadequate social support, and social inconvenience" (Olsson et al., 2008, p. 365). A limitation of this study may be that adolescents already feel low self-esteem and an increased desire to be accepted by peers during this stage of development. More research is needed in a wider age group to determine the influence social pressures have over individuals with CD and compliance or non-compliance with the GFD (Olsson et al., 2008).

Gluten-Free Food Availability

Availability of GF foods seems to be a factor for compliance and was mentioned in both studies lead by Lee and Olsson. Another study conducted by Zarkadas and colleagues in 2006 also mentions the influence availability of GF foods has on the rate of compliance with the GFD (Zarkadas, Cranney, Case, Molloy, Switzer, Graham et al., 2006). The study assessed 2,681 CD individuals who were members of the Canadian Celiac Association (CCA) to evaluate the impact the GFD has on CD individuals. Zarkadas found that 15-20% of participants reported having difficulty with availability of GF foods most of the time (Zarkadas et al., 2006). No studies were found that directly focused on availability of GF foods and the connection to GFD compliance. Further research is needed to determine if availability of GF foods has a significant impact on compliance or non-compliance with the GFD.

Physiological Influences

The presence or absence of physiological symptoms may be a factor for determining compliance or non-compliance with the GFD for CD individuals. A study published in 2004 by Murray and colleagues aimed to examine the effect of the GFD on gastrointestinal symptoms of CD (Murray, Watson, Clearman, & Mitros, 2004). "A cohort of US patients evaluated at the University of Iowa from 1990 to 1997 was systemically surveyed about gastrointestinal symptoms before and after adhering to the GFD" (Murray et al., 2004, p. 669). Prior to starting a GFD, 75% of participants said they experienced diarrhea and more than half of those with diarrhea reported stools suggestive of steatorrhea. "Sixty-one percent complained of frequent flatulence, and 64% had urgency. Thirty-one percent complained of significant tenesmus, and 38% had experienced fecal incontinence" (Murray et al., 2004, p. 669). The study found that the GFD was beneficial for both men and women at improving the presence of diarrhea, constipation, abdominal pain, bloating, and nausea or vomiting. Sixty-one percent of participants who had diarrhea originally reported resolution by six months after compliance with the GFD. The study concluded that the GFD will significantly reduce gastrointestinal symptoms of CD ($p<0.001$) (Murray et al., 2004). Although not explicated stated by the study, it may be hypothesized that compliance may increase with the decrease of gastrointestinal symptoms. Further research is needed to determine the accuracy of the hypothesis.

Summary

CD has become more prevalent in the past decades affecting nearly three million Americans (Fasano et al., 2003). It is important for practitioners to have a working understand of the condition in order to recognize symptoms, improve diagnostic time, and reduce the risk of developing additional complications (Martin, 2008). Strict compliance with the GFD is reported to provide protective benefits for CD patients from GI malignancies (Seraphin & Mobarhan, 2002)). Research conducted by Corrao et al. in 2002 reported by Seraphin showed this association and reported a relation between GFD compliance and decreased mortality rates in both symptomatic and asymptomatic CD patients. A standardized mortality ratio (SMR) was calculated over a 6-year study that showed an increase in deaths from small bowel lymphoma and other malignant diseases in patients not following the GFD (Seraphin & Mobarhan, 2002). Additional research is needed to determine the effects of malignant diseases associated with CD to better understand the relation with the GFD. Further research is needed to determine influential factors for compliance and/or non-compliance to the GFD in order to improve education strategies for effective treatment of CD using the GFD.

Chapter 3

METHODOLOGY

The purpose of this study is to determine the influential factors of compliance and/or non-compliance with the GFD for CD individuals. Research found that strict adherence with the GFD provides protective effects for the CD individual. This section discusses the design of the study, the sample, instrumentation, procedure for data collection and data analysis.

Design of the Study

The design of this study is a mixed-method survey analysis. There was one group of participants consisting of CD support group members from nine Midwestern states. Each participant followed the same research procedures.

Sample

Members of CD support groups based in Midwestern states (Illinois, Indiana, Iowa, Kansas, Michigan, Minnesota, Missouri, Ohio, and Wisconsin) were recruited for participation (See appendix A). A minimum of 50 members were required to provide a basis for estimating sampling error. To achieve the minimum sample, participation from multiple CD support groups within each state was necessary.

Selection of sample

The sample was selected based on convenience. All members agreeing to participate were included in the study. Electronic correspondence was initiated with the head of each CD support group, requesting participation from other members of the group. Participation was completely voluntary. No age or gender quota was established. Parents or legal guardians of minors (17 years of age or younger) with CD helped fill out

electronic surveys if they desired and by doing so gave consent for the minor. Participants were informed the study was voluntary and that they could withdraw at any point during the research project.

Instrumentation

The instrument used to conduct research in this study was a researcher-developed survey on CD and the GFD (see appendix B) using kwiksurveys.com. The survey was designed to collect data on influential factors for CD individuals in determining GFD compliance and/or non-compliance. Reliability of the instrument has not been established because this was the initial distribution of the survey. Face validity was established via peer review. Content validity was established via review by two experts in the field of nutrition and dietetics. Due to the Midwestern focus of the data, ecological validity for other regions of the United States like the east or west coast cannot be established.

Procedure for Data Collection

Participants were contacted via email and told that the focus of the research was to collect data on CD and the GFD. To avoid influencing the responses, the participants were not informed of the specific focus of the research (developing educational strategies for effective treatment of CD using the GFD by better understanding influences on compliance). Participant names and contact information were available to the researcher but excluded from the results. Participants were informed in the recruitment email about the purpose of the study, procedures, potential risks and discomforts, benefit of participation, confidentially, right to withdraw, and contact information for additional questions or concerns. By responding to the invitation to participate email, participates

gave informed consent. The link to the online survey was administered through email. Participants completed the survey online via the kwiksurverys.com website. Individual surveys were not seen by anyone other than the researcher and names of participants were kept confidential. After initial distribution of the link to the survey on June 1, 2010, participants had 2 weeks to complete the survey online. After 2 weeks, the number of completed surveys were counted and the need for reminder emails and further participant recruitment was assessed. Reminder emails were sent to additional potential participants and the link was closed on June 30, 2010.

Data Analysis

Surveys were analyzed by kwiksurvey.com and a report was generated to present descriptive statistics using tables, frequencies, means, and ranges for questions one through eleven. Emerging themes and patterns of qualitative data in question 12 were tallied and reported using frequencies generated by kwiksurvey.com and discussed in a narrative form. Regression analysis using SPSS was used to determine the influential factors that predict compliance and/or non-compliance with the GFD and established statistical significance at $p \leq 0.05$.

Chapter 4

RESULTS AND DISCUSSION

The purpose of this study was to determine the influential factors of compliance and/or non-compliance with the GFD for CD individuals. Currently, there is no known cure for CD and the most common treatment is strict adherence with the GFD. However, not all individuals diagnosed with CD are successful at following the GFD as closely as necessary for proper recovery from and prevention of symptoms. Research question number one asked if age of diagnosis would predict compliance and/or non-compliance with the GFD. Research question number two asked if knowledge of the GFD would predict compliance and/or non-compliance with the GFD. Research question number three asked if availability of GF foods would predict compliance and/or non-compliance with the GFD. Research question number four asked if social pressures and situations would predict compliance and/or non-compliance with the GFD. Question number five asked if the severity of physical symptoms of CD would predict compliance and/or non-compliance with the GFD. Question number six asked if the cost of GF foods would predict compliance and/or non-compliance with the GFD.

Results

The snowball effect enhanced distribution of the online survey and increased the response rate. Ninety initial invitation emails were sent to CD support group facilitators. Of the original 90, 30 (33%) completed surveys were received. An additional 60 reminder emails were sent after the first 2 weeks and generated a response from 123 CD support group members. Of the total 153 surveys received, four were excluded from the analysis due to unanswered questions. Another three were excluded for being out of the

predetermined nine states. Data from a total of 146 completed surveys were analyzed. Demographic data, descriptive statistics and multiple regression analysis using kwiksurveys.com and SPSS software were used to analyze the responses from questions one through 11. Responses to the qualitative question number 12 were examined by the researcher and reported in narrative from.

Demographic Data

Of the 146 participants, 129 (88.4%) were female and 17 (11.6%) were male (ratio 7.5/1). Participants ranged in age from 5-78 years old (mean= 45 ± 17 years) and the majority of participants were between the ages of 41-60 years old. The majority of participants were from Wisconsin at 27.4% (40), 15.1% (22) were from Illinois, 14.4% (21) were from Michigan, 10.3% (15) were from Missouri, 8.9% (13) were from Kansas, 8.9% (13) were from Minnesota, 7.5% (11) were from Ohio, 4.1% (6) were from Iowa, and 3.4% (5) were from Indiana. The demographic data are shown in Table 1 and the state distribution is illustrated in Figure 1.

Table 1

Characteristics of CD Support Group Facilitators and Members

Characteristics	(N=146)	%
Current Age (years)		
1-20	13	8.9
21-40	39	26.7
41-60	63	43.2
61-80	31	21.2
Gender		
Male	17	11.6
Female	129	88.4

Figure 1

State Distribution of Participants

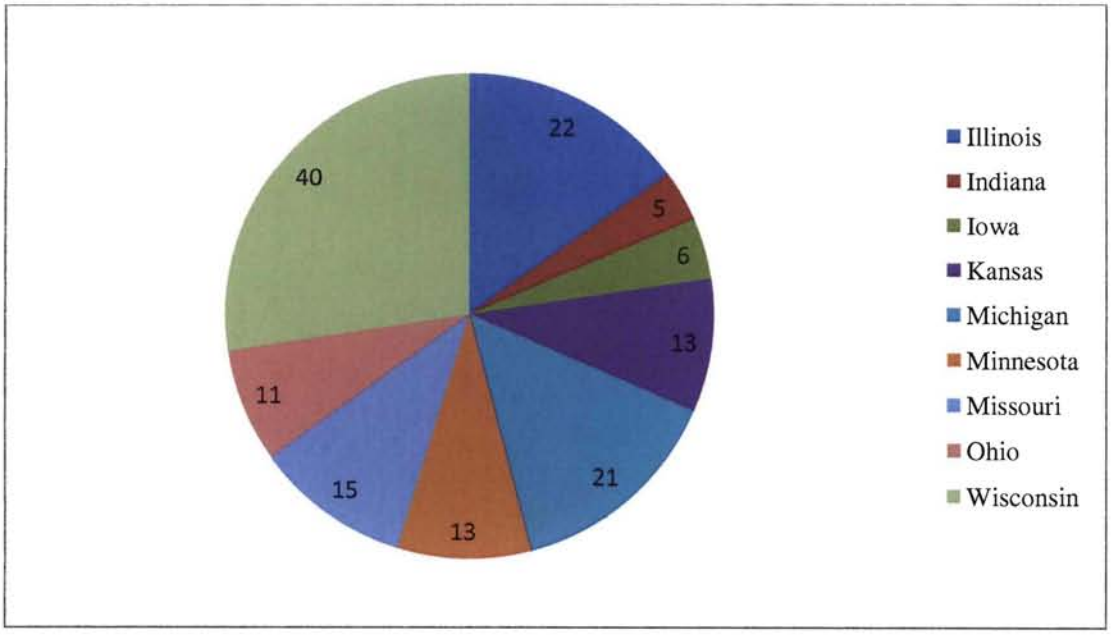

Figure 1. Note. Each participant indicated their current state of residence. The percentage of participants from each state is illustrated by the graph.

Research Question 1: Does age of diagnosis of CD predict compliance and/or non-compliance with the GFD?

Participants indicated their age at diagnosis in question number four on the survey. Participants ranged in age at diagnosis from 1-74 years old with the mean being 39 ± 17 years (female=38.8 ± 16.4 years, male=40.7 ± 21.7 years). The majority of participants were diagnosed between the ages of 21-60. Table 2 shows the distribution of age at diagnosis among participants. Age of diagnosis was negatively correlated with current rate of compliance (beta= -0.109). The negative correlation suggests that a change in rate of compliance reflects an inverse change in age. This change signifies a trend in the data that the younger the age of diagnosis, the higher the rate of compliance. Linear regression analysis using SPSS indicates that age at diagnosis can independently account for 1.2% of the variance in current rate of compliance ($p>0.05$). Although not statistically significant alone, when combined with current knowledge of the GFD, availability of GF foods, and influence of social pressures and situations in stepwise multiple regression analysis, 24.0% of the variance in current rate of compliance can be explained. This indicates that these four factors play a key role in determining current rate of compliance.

Table 2

Distribution of Age at Diagnosis for Participants

Age at Diagnosis	(N=146)	%
1-20	19	13.0
21-40	55	37.7
41-60	59	40.4
61-80	13	8.9

Research Question 2: Does knowledge of the GFD predict compliance and/or non-compliance with the GFD?

Participants rated their current knowledge of the GFD in questions number five on the survey. Participants had a mean response of 9.3 ± 1.4 (10 being 100% knowledgeable and 1 being 100% not knowledgeable) indicating the majority of participants believed themselves to be 90% knowledgeable of the GFD. There was no significant difference between male and female (male= 9.1 ± 1.7, female= 9.3 ± 1.4) responses. Figure 2 illustrates frequency of responses. Current knowledge was positively correlated with current rate of compliance (beta = 0.365). Linear regression analysis using SPSS indicates that current knowledge of the GFD can independently account for 13.3% of the variance in current rate of compliance ($p>0.05$). Although not statistically significant alone, when combine with availability of GF foods, age at diagnosis, and influence of social pressures and situations in stepwise multiple regression analysis, 24.0% of the variance in current rate of compliance can be explained. Again, indicating that these four factors play a key role in determining current rate of compliance for CD individuals.

Figure 2

Frequency of Responses of Self-Rated Knowledge of the GFD.

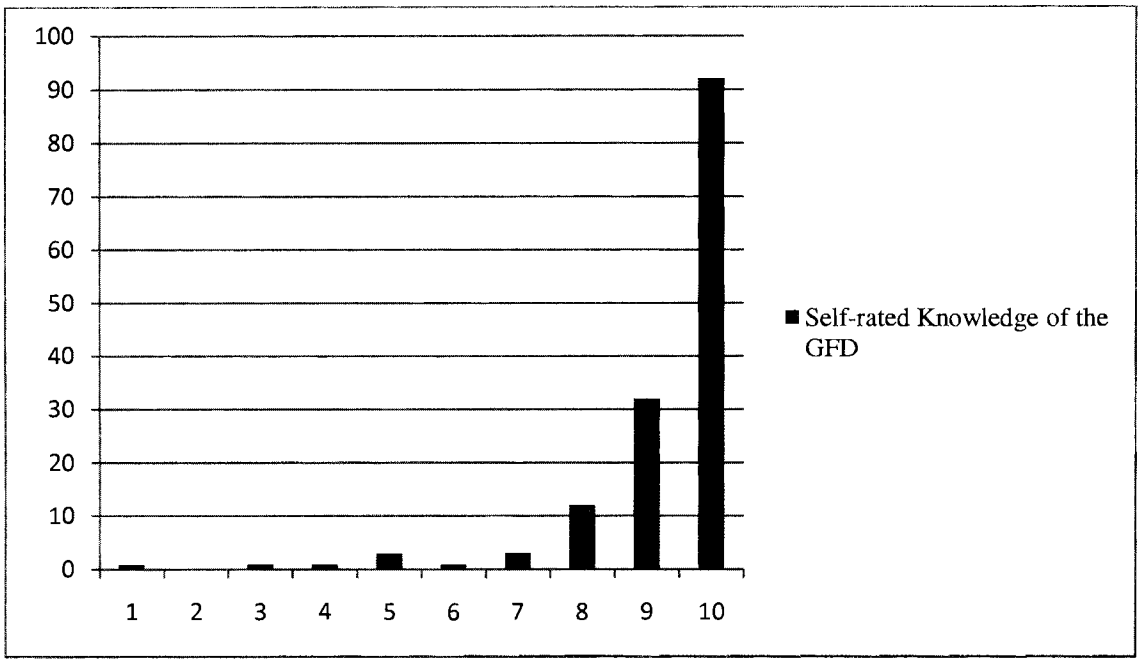

Figure 2. Note. The y-axis is the number of participants. The x-axis is the response indicated by each participant on the survey (1 to 10) of self-rated knowledge of the GFD.

Research Question 3: Does the availability of GF foods predict compliance and/or non-compliance with the GFD?

Participants rated the availability of GF foods where they lived in question number seven on the survey. The mean response was 7.7 ± 2.0 (10 being 100% always available and 1 being 100% never available) indicating the majority of participants believed GF foods to be 77% available where they lived. Eleven percent of participants (17) reported GF foods to be available <50% of the time. There was no significant difference between male and female (male= 7.2 ± 2.5, female= 7.8 ± 2.0) responses. Figure 3 illustrates frequency of responses. Availability was positively correlated with current rate of compliance (beta = 0.303). Linear regression using SPSS indicates that

availability can independently account for 9.2% of the variance in current rate of compliance. Although not statistically significant alone, when combined with current knowledge, age at diagnosis, and influence of social pressures and situations in stepwise multiple regression analysis, 24.0% of the variance in current rate of compliance can be explained. Availability of GF foods is one of the four key components in determining current rate of compliance for CD individuals.

Figure 3

Frequency of Responses to Availability of GF Foods

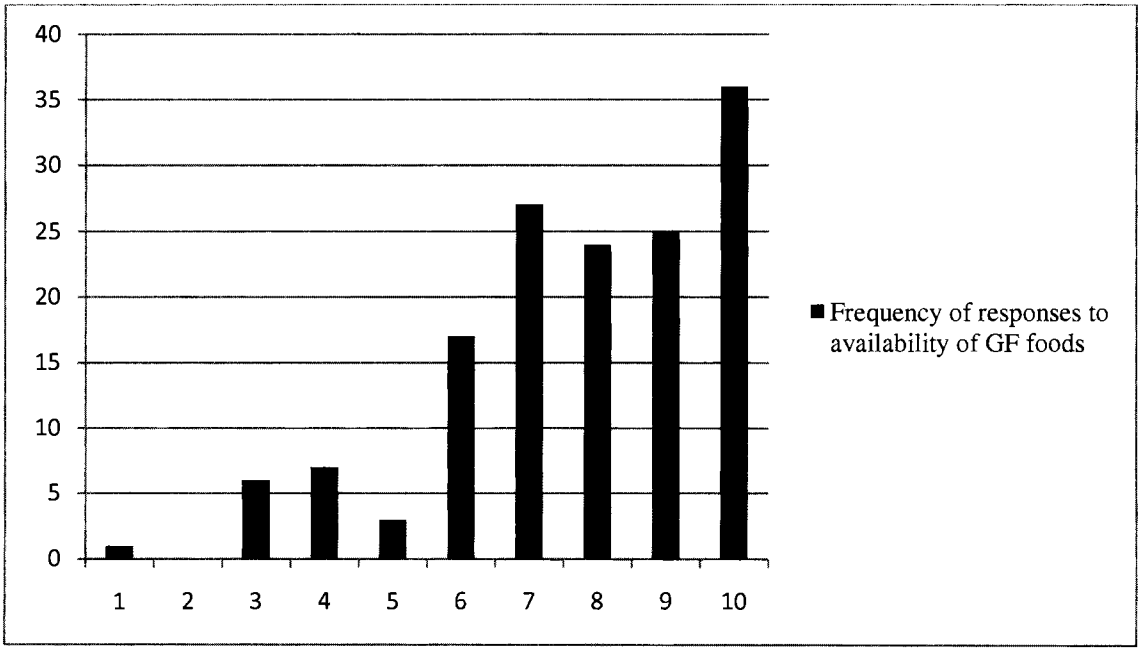

Figure 3. Note. The y-axis is the number of participants. The x-axis is the response indicated by each participant on the survey (1 to 10) of availability of GF foods.

Research Question 4: Do social pressures and situations predict compliance and/or non-compliance with the GFD?

Participants rated how influential social pressures and situations were to their decision to comply with the GFD in question number eight on the survey. The mean response was 2.8 ± 2.7 (10 being 100% always influential and 1 being 100% never influential) indicating the majority of participants believe social pressures and situations to be minimally influential on compliance. Male participants tend to be more influenced by social pressures and situations (male= 4.2 ± 3.4) than female participants (female= 2.6 ± 2.6). Figure 4 illustrates frequency of responses. Influence of social pressures and situations were negatively correlated with current rate of compliance (beta = -0.210). Linear regression using SPSS indicates that influence of social pressures and situations can independently account for 4.4% of the variance in current rate of compliance. Although not statistically significant alone, when combined with current knowledge of the GFD, age at diagnosis, and availability of GF foods in stepwise multiple regression analysis, 24.0% of the variance in current rate of compliance and be explained. This result indicates that these four components are important in determining current rate of compliance for CD individuals.

Figure 4

Frequency of Responses to Influence of Social Pressures and Situations.

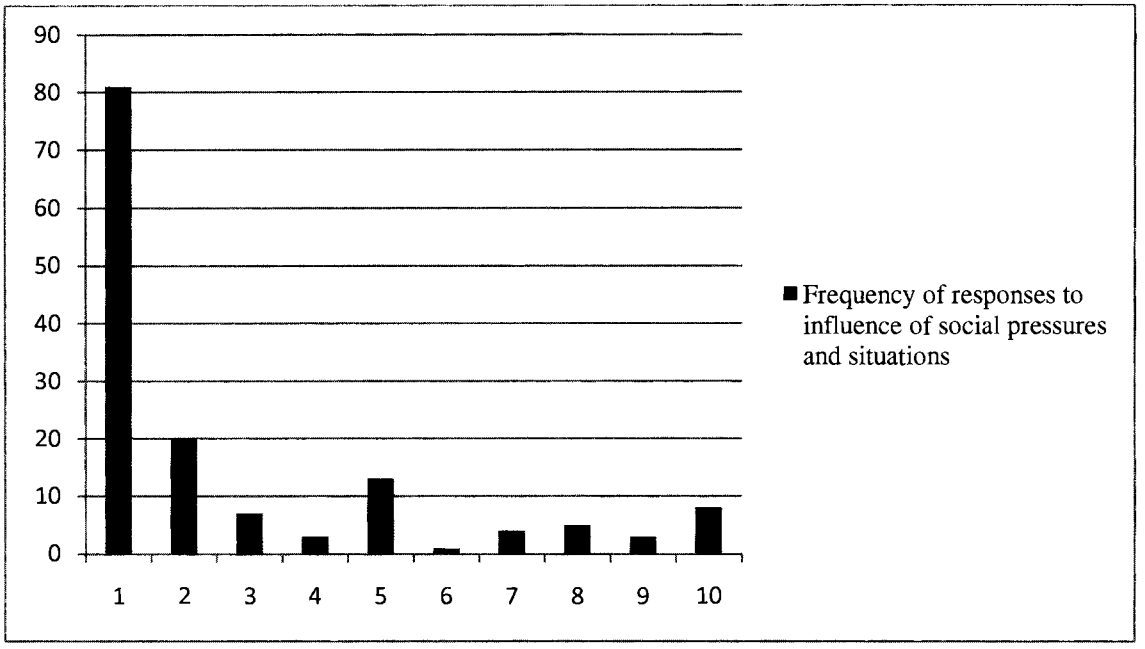

Figure 4. Note. The y-axis is the number of participants. The x-axis is the response indicated by each participant on the survey (1 to 10) of influence of social pressures and situations on compliance with the GFD.

Research Question 5: Does the severity of physical symptoms of CD predict compliance and/or non-compliance with the GFD?

Participants rated the severity of their physical symptoms of CD in questions number nine on the survey. The mean response was 6.7 ± 2.9 (10 being 100% always severe and 1 being 100% never severe) indicating that the majority of participants found their physical symptoms to be 67% severe. There was no significant difference between male and female (male=6.6 ± 3.1, female=6.7 ± 3.0) responses. Figure 5 illustrates frequency of responses. Physical symptom severity was positively correlated with current rate of compliance (beta = 0.018). Although an important factor, severity of

physical symptoms was not statistically significant when determining current rate of compliance.

Figure 5

Frequency of Responses to Severity of Physical Symptoms

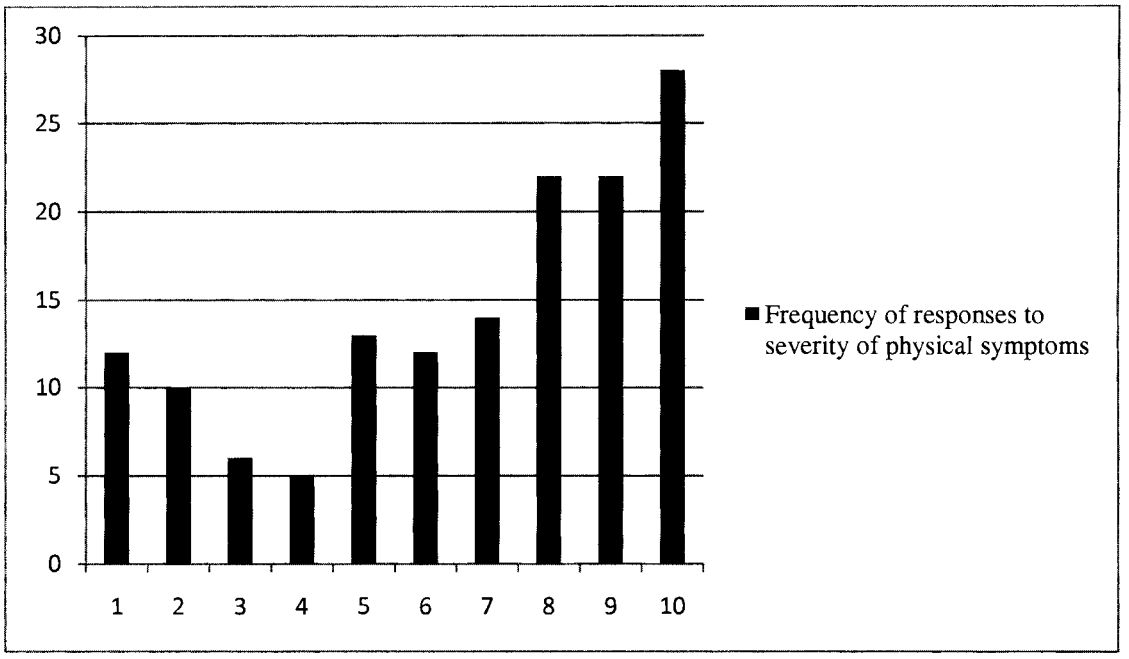

Figure 5. Note. The y-axis is the number of participants. The x-axis is the response indicated by each participant on the survey (1 to 10) of severity of physical symptoms.

Research Question 6: Does the cost of GF foods predict compliance and/or non-compliance with the GFD?

Participants rated how expensive they found GF foods to be in question number ten on the survey. The mean response was 8.7 ± 1.3 (10 being 100% always expensive and 1 being 100% never expensive) indicating participants find GF foods to be more expensive than their gluten-containing counterpart 87% of the time. There was no significant difference between male and female (male= 8.8 ± 1.3, female= 8.7 ± 1.3) responses. Participants were then asked in question number 11 on the survey to rate how

influential the cost of GF foods are on their decision to comply with the GFD. The mean response was 2.6 ± 2.7 (10 being 100% always influential and 1 being 100% never influential) indicating participants are influenced by the cost of GF foods 26% of the time. Male participants seemed to be more influenced by cost (male= 4.0 ± 3.8) than female participants (2.4 ± 2.5). Figure 6 illustrates frequency of responses. Cost of GF foods was negatively correlated to current rate of compliance (beta = -0.221). Although participants found GF foods to be expensive, they were not significantly influenced by the cost.

Figure 6

Frequency of Responses to Perceived Cost vs. Influence of Cost

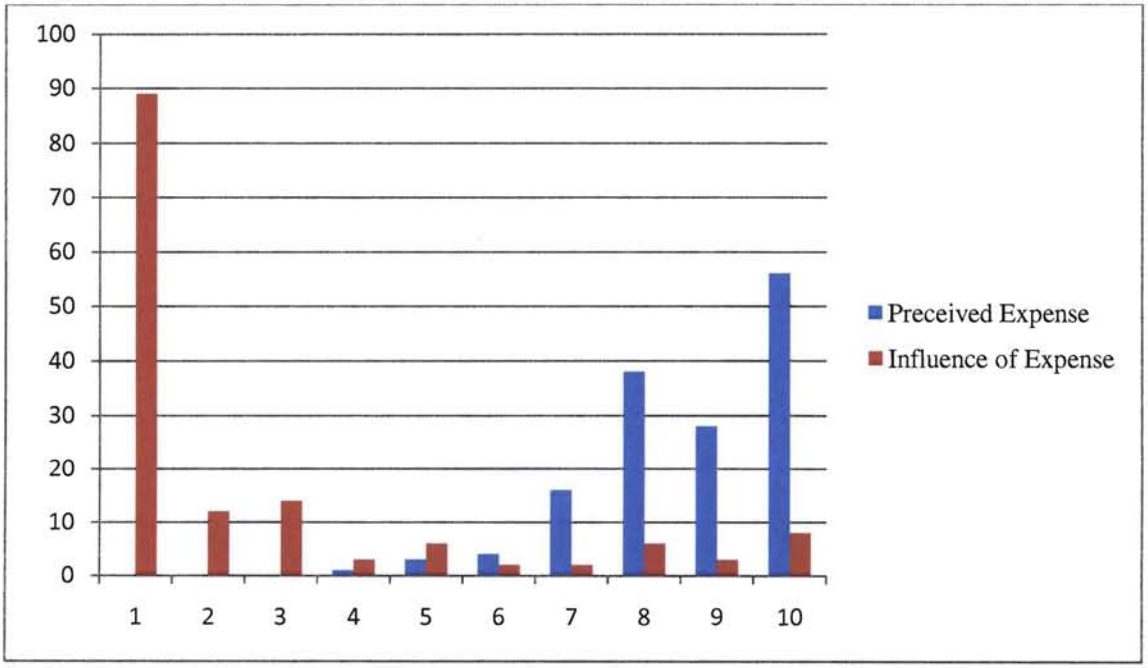

Figure 6. Note. The y-axis is the number of participants. The x-axis is the response indicated by each participant on the survey (1 to 10) of perception of cost of GF foods as well as influence of cost of GF foods on compliance with the GFD.

Qualitative data: Survey questions 12

Question 12 on the survey asked participants to share any experiences they have had while eating a GFD. One hundred participants responded to question 12 which were analyzed for common themes. Participants reported challenging situations related to eating a GFD as well as strategies they developed to overcome those challenges. Common challenges were eating out (30%), fears of cross-contamination while eating out (17%), severity of physical symptoms (16%), high cost of GF foods (14%), lack of or miss information/knowledge of others (8%), traveling (5%), social pressures (4%), school lunches (4%), availability of GF foods (3%), and cross-cultural challenges (1%).

Eating out and cross-contamination presented the most difficult challenge for the majority of participants. Many indicated it was because of lack of options of GF foods on the menu, cross-contamination with gluten-containing foods in the kitchens, lack of education among kitchen staff and wait staff, and restaurants giving out miss or false information. Some participants reported it was easier to eat at home than try to find something that was safe on a menu at a restaurant. For example, one participant shared about the difficultly of going out to eat

'Very difficult to go out to eat so we rarely do because of the high risk involved.' (Male, 35 years)

Other participants described strategies for going out to eat that allow them to still enjoy dining out like anyone else. For example, one participant shared a strategy for finding GF foods.

'There are now a number of restaurants in my area that have fresh gluten-free meals available and I always call the restaurants ahead of time'. (Female, 28 years)

Participants reported physical symptoms to be a challenge associated with CD and the GFD. Many reported that pain and discomfort was a reminder to stick to the diet and that any exposure to gluten would cause almost immediate bloating, cramps, and abdominal discomfort. This physical distress was enough to help the majority of participants maintain compliance with the GFD. For example, one participant shared her experience with the GFD.

'I just remember that nothing tastes as good as being healthy feels'. (Female, 24 years)

The high cost of GF foods was also mentioned by participants as a challenge when trying to comply with the GFD. Many reported needing to find specialty food stores to locate GF products which would always be more expensive than normal grocery stores. Prepackaged GF products like baking mixes, snack foods, and breads were considered the most expensive GF foods by participants. For example, one participant shared her experience buying GF bread.

'I now drive 45 minutes for bread that costs $5 and it only has 12 slices'. (Female, 30 years)

One participant reported a strategy for avoiding high costs of GF foods by shopping online. Online grocery stores offer foods at a less expensive price than in-person grocery stores as well as allowing access to a wider variety of GF products nationwide which may not be available in the local area.

Participants indicate that the lack of knowledge or miss information of others creates a challenge when trying to comply with the GFD. Miss or lack of information from friends, family, restaurant staff, health care professionals, teachers, co-workers, the

media, and food labels present a challenge to the CD individual. Participants suggested increasing education on CD in all areas to increase awareness of the condition and improve CD related information they receive.

Traveling presents another challenge for CD individuals. Airports, different cities, and different countries were mentioned as the most challenging places to eat while traveling. Participants suggested bringing snacks and planning ahead when taking trips to avoid moments of non-compliance.

Social pressures were mentioned by 4% of participants as a challenge for compliance with the GFD. Feelings of embarrassment, being a burden, causing a scene, not wanting to look different and not wanting to hurt someone's feelings were mentioned when discussing challenges with compliance. Of the 4% indicating social pressures as a challenge, most reported lack of knowledge of peers in social situations to create the issue surrounding compliance. For example, one participant shared his feelings about eating with others.

'People give you a hard time about not eating certain foods and don't understand why you can't eat them'. (Male, 30 years)

Educating others within social circles was a strategy one participant mentioned for decreasing the influence of social pressures on compliance with the GFD. Incorporating family and friends into the dietary counseling treatment of CD may help to address this issue.

School lunches provided by the school lunch program presented a challenge for school age participants. Children feeling left out because of food and the risk of cross-contamination due to uneducated kitchen staff create a challenge with compliance.

Parents of CD children suggested acting as an advocate and requesting school cooks to become educated about the condition as a strategy for helping their CD children increase compliance.

Availability of GF foods as a challenge of compliance was only mentioned by 3% of participants in questions number 12 which is consistent with the response to question number seven. Availability of GF products is increasing and participants are finding it easier to purchase foods that are safe. Participants rated GF foods to be 77% available indicating the majority of participants do not find availability of GF foods to be a challenge associated with complying with the GFD. Of the 3% indicating availability as a challenge, the majority lived in rural areas and also mentioned an increase in the availability of GF products over time. For example, one participant shared her experience with the GF diet over 20 years with CD.

'Very different at the beginning, 20 years ago-little to nothing available commercially. Now, things are popping up all over-that has been a nice change'. (Female, 68 years)

Cross-cultural challenges were mentioned by one participant. Different cultural foods that CD patients are unfamiliar with, different preparation methods and the language barrier all present a challenge for compliance with the GFD. For example, the participant shared her experience with the language barrier in another country.

'Trying to explain that you are gluten-free to a waiter here in the states is difficult, then try to do it with someone who does not speak English. Makes it much harder' (Female, 21 years)

The responses to survey question 12 consistently agreed with the quantitative responses to questions 1-11. The common challenges and strategies presented by participants support the findings of this study.

Discussion

CD is a much more common place disease today than it was only a few decades ago affecting 1 in 133 people in the United States (Fasano et al., 2003). Currently, there is no known cure for CD and, if left untreated or undiagnosed, CD can have multiple severe complications on the individual's health. Strict adherence with the GFD is life-long and presents a challenge for many individuals that are influenced by various factors. The purpose of this study was to determine the influential factors of compliance and/or non-compliance with the GFD for CD individuals. Understanding compliance rates will help to improve education strategies for effective treatment of CD using the GFD. A survey was developed and distributed to CD support group facilitators from nine Midwestern states online using kwiksurveys.com to determine influential factors contributing to compliance and/or non-compliance.

Hypothesis 1: Early Diagnosis of CD will predict significantly improved compliance with the GFD.

The results from question four indicate that the majority of participants were diagnosed with CD between the ages of 21 and 60. Hypothesis 1 predicts that the earlier a patient is diagnosed with CD, the higher their rate of compliance with the GFD will be. Although the results point toward a negative trend, the relationship is not statistically significant ($p \geq 0.05$) and hypothesis 1 cannot be accepted alone. This finding contradicts with the findings of Hauser, Stallmach, Caspary, and Stein (2007) that reported the

younger the individual is at diagnosis corresponds with a decrease in their sense of well-being (beta= -0.04, p=0.69). Hauser predicts that early age of diagnosis will decrease compliance due to a decrease in coping skills at an early age. As the CD individual grows, lack of coping skills may result in continued issues with compliance throughout life (Hauser et al., 2007).

In the current study, when age at diagnosis was considered with participants' responses to availability of GF foods, current knowledge of the GFD, and the influence of social pressures and situations, it played a role in determining rate of compliance; knowing the above four factors accounts for 24.0% of the variance in current rate of compliance. This finding is unique to the current study. No other studies have been published that address the specific four factors listed above.

Hypothesis 2: Increased knowledge of the GFD will predict significantly improved compliance with the GFD.

The results from question five indicate the majority of participants believe themselves to be 90% knowledgeable of the GFD. Hypothesis 2 predicts the more knowledge a CD individual has, the higher their rate of compliance will be. The results point toward a positive trend showing an increase in knowledge of the GFD predicts an increase in current rate of compliance 13.3% of the time. Current knowledge of the GFD alone is not statistically significant ($p \geq 0.05$) in predicting current rate of compliance and hypothesis 2 is rejected. In a study conducted by Anson (1990) aimed at assessing parental knowledge of the GFD and compliance rates for their CD children, they found that parents of compliance CD children could name all the GF foods from a menu (94%), understood the diet was for life (52%), and that CD affects the absorption of foods (70%).

They concluded that an increase in parental knowledge of CD and the GFD increased compliance for their CD children (Anson, Weizman, & Zeevi, 1990). These results agree with the current study that shows a positive correlation between increased knowledge of the GFD and increased compliance with the GFD.

In the current study, when knowledge of the GFD is considered with participants' responses to availability of GF foods, age at diagnosis and influence of social pressures and situations, 24.0% of the variance in current rate of compliance is explained. There is a lack of research focused on these four factors and their contribution to current rate of compliance with the GFD. Further research is needed to determine the reliability of the current study's results.

Hypothesis 3: Availability of GF foods will predict significantly improved compliance with the GFD.

The results from question seven show the majority of participants believe GF foods to be 77% available where they live. Hypothesis 3 predicts the more availability of GF foods, the higher the rate of compliance with the GFD will be. Availability of GF foods is positively correlated with current rate of compliance suggesting an increase in availability of GF foods will predict an increase in current rate of compliance 9.2% of the time. Alone, availability of GF foods is not statistically significant ($p \geq 0.05$) at predicting current rate of compliance and hypothesis 3 is rejected. However, when considered as a component with current knowledge of the GFD, age at diagnosis, and the influence of social pressures and situations, 24.0% of the variance in current rate of compliance is explained. This finding concerning availability alone is consistent with the research done by Zarkadas assessing the impact of the GFD for CD individuals. Zarkadas and

collegues found that 15-20% of participants are influenced by availability of GFD (Zarkadas et al., 2006). There is a lack of research surrounding availability of GF foods and its impact on compliance with the GFD. Further research is needed on this issue alone and as a part of a multi-factorial influence on compliance.

Hypothesis 4: Social situations will increase pressure which will predict significantly decreased compliance with the GFD.

The results from question number eight on the survey show the majority of participants (n=81) are not significantly influenced by social pressures and situations. Hypothesis 4 predicts that social situations will increase pressure to decrease compliance with the GFD. Although the influence of social pressures and situations were negatively correlated with current rate of compliance, the relationship is not statistically significant ($p \geq 0.05$) and hypothesis 4 is rejected. These results correspond with the majority of participants (85%) saying social pressures and situations do not influence their decisions to comply with the GFD >50% of the time. Research findings from Olsson et al. (2008) focused on adolescents disagrees with these findings, saying feelings of embarrassment and not wanting to be a burden to others fuel non-compliance. The differences in results may be explained by the differences in mean ages of study samples. Adolescents may be more influenced by social pressures and situations than adults and older adults.

In the current study, when influence of social pressures and situations is considered as a component with availability of GF foods, current knowledge of the GFD, and age at diagnosis, it predicts 24.0% of the variance in current rate of compliance. There is a lack of research focused on these four factors and their contribution to current

rate of compliance with the GFD. Further research is needed to determine the reliability of the current study's results.

Hypothesis 5: Severe physical symptoms of CD will predict significantly increased compliance with the GFD.

The results from question number nine on the survey indicate that participants found their physical symptoms to have a wide range in severity. Hypothesis 5 predicts that the more severe the physical symptoms from CD, the higher the rate of compliance with the GFD. Although there is a positive correlation, severity of physical symptoms only predicts an increase in current rate of compliance 1.8% of the time. The relationship is not statistically significant ($p \geq 0.05$) and hypothesis 5 is rejected. Further research is needed to determine if severity of physical symptoms determines compliance; however, one study by Murray et al. (2004) reported that compliance with the GFD significantly reduced gastrointestinal symptoms of CD ($p=0.001$) (Murray et al., 2004). Murray et al. indicate that compliance increases as symptoms decrease to maintain a feeling of good health.

Hypothesis 6: The high cost of GF foods will predict significantly decreased compliance with the GFD.

The results from questions 10 and 11 on the survey show participants find GF foods to be more expensive than their gluten-containing counterpart 87% of the time but are influenced by the price 26% of the time. Hypothesis 6 predicts that the higher cost of GF foods will decrease compliance with the GFD. Perceived expense is positively correlated with current rate of compliance and predicts increased compliance 1.3% of the time, but is not statistically significant ($p \geq 0.05$). Influence of expense is negatively

correlated with current rate of compliance and predicts a decrease in compliance 22.1% of the time, but it is not statistically significant ($p \geq 0.05$) and hypothesis 6 is rejected. The findings on perceived expense agree with Lee et al. (2007) study which concluded that GF foods are considerably more expensive than gluten-containing foods.

Qualitative data

The qualitative data collected with question 12 is consistent with the quantitative data collected with questions 1-11. The wide variety of challenges and strategies illustrate that compliance with the GFD is still an individualized issue. It also shows that more than one factor contributes to the decision process of CD individuals when considering compliance and non-compliance. This idea is supported in literature by studies conducted here in the United States and around the world. Olsson et al. (2008) concluded that adolescents face various influences associated with eating a GFD such as limited knowledge, limited availability of GF foods, feelings of embarrassment, and taste of GF foods. Zarkadas et al. (2006) concluded that CD individuals will improve compliance if provided with better food labels, better dietary instruction, increased availability of GF foods, and earlier diagnosis of the disease. Lee et al. (2007) found that the GFD presents a financial burden to CD individuals and may determine compliance. Previous research and the current study are consistent with the conclusions that compliance is a multi-factorial issue for CD individuals.

Chapter 5

SUMMARY AND CONCLUSIONS

The prevalence of CD is growing, affecting 1 in 133 people in the US today (Fasano et al., 2003). There is no known cure for CD and the only treatment is strict dietary changes eliminating gluten. It is important as a practitioner to have a functional understanding of the condition to recognize symptoms, improve diagnostic time, and reduce the risk of developing additional complications (Martin, 2008). Adherence to the GFD will relieve physical symptoms, allow the small intestine to heal, and the process of malabsorption and malnutrition to be reversed.

Summary

Compliance with the GFD is a life-long change that presents a challenge to CD individuals. Factors influencing compliance are numerous and diverse. The purpose of this research project was to determine the influential factors of compliance and/or non-compliance with the GFD for CD individuals. The researcher hypothesized that early diagnosis of CD would predict significantly improved compliance with the GFD. Increased knowledge of the GFD would predict significantly improved compliance with the GFD. Availability of GF foods would predict significantly improved compliance with the GFD. Social situations would increase pressures that would predict significantly decreased compliance with the GFD. The severity of physical symptoms of CD would predict significantly improved compliance with the GFD. And that the high cost of GF foods would predict significantly decreased compliance with the GFD.

A survey was developed by the researcher and distributed online to a convenience sample of CD support group facilitators in nine Midwestern states (Illinois, Indiana,

Iowa, Kansas, Michigan, Minnesota, Missouri, Ohio, and Wisconsin). The survey was composed of 12 questions pertaining to influential factors contributing to compliance and/or non-compliance. The researcher found that age at diagnosis, knowledge of the GFD, availability of GF foods, and influence of social pressures and situations accounted for 24.0% of the variance in current rate of compliance with the GFD. The qualitative data from question 12 found that the decision to comply with the GFD is multi-factorial and individualized. These findings were not statistically significant and the researcher rejected the hypotheses; however, the data trend is in a positive direction and, with a larger sample, significant findings may be observed.

Recommendations for Future Research

Further research on factors contributing to compliance with the GFD is needed. There was a lack of research addressing the specific factors related to compliance. Studies focused on age at diagnosis and compliance with the GFD is needed to determine if early diagnosis of CD will significantly affect compliance. Studies that measure knowledge of the GFD and its effect on compliance are needed to determine if a significant relationship exists. Research concerning availability of GF foods and how availability effects compliance as well as studies on the influence of physical symptoms and their effect on compliance are needed. Research aimed at determining the influence of social situations and compliance and the influence of cost of GF foods and compliance with the GFD are needed to assess significant impact on compliance.

Recommendations for Practice

The findings of this research can be applied to the future practice of registered dietitians and their dietary counseling of CD patients using the GFD. The study found a

trend in the data suggesting knowing the patient's age at diagnosis, current knowledge of the GFD, availability of GF foods where they live, and the influence of social pressures and situations can help determine the current rate of compliance with the GFD for that patient. Although not the only factors contributing to compliance, these four components account for 24.0% of the variance in compliance rates for CD individuals living in the Midwest. Encouraging early diagnostic screening for CD, education on the GFD, access to GF foods, and strategies for overcoming social pressures and situations seem to be important tools for increasing compliance with the GFD for CD individuals.

Conclusion

CD has become more prevalent in the past decades affecting nearly three million Americans (Fasano et al., 2003). It is important for practitioners to have a working understand of the condition in order to recognize symptoms, improve diagnostic time, and reduce the risk of developing additional complications (Martin, 2008). Strict compliance with the GFD is reported to provide protective benefits for CD patients from GI malignancies (Seraphin & Mobarhan, 2002)). Research conducted by Corrao et al. in 2002 reported by Seraphin showed this association and reported a relation between GFD compliance and decreased mortality rates in both symptomatic and asymptomatic CD patients. A standardized mortality ratio (SMR) was calculated over a six year study that showed an increase in deaths from small bowel lymphoma and other malignant diseases in patients not following the GFD (Seraphin & Mobarhan, 2002). Additional research is needed to determine the effects of malignant diseases associated with CD to better understand the relation with the GFD.

The current study concludes that 24.0% of the variance in current rate of compliance can be explained by knowing the patient's age at diagnosis, knowledge of the GFD, availability of GF foods where they live, and the influence of social pressures and situations. Understanding these and other factors influencing compliance rates is important for health care practitioners in order to improve educational strategies for effective treatment of CD using the GFD.

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Appendix A

Dear Celiac Disease Support Group members,

You are invited to participate in a research study on celiac disease and the gluten-free diet being conducted by Jill Barnes, a graduate dietetics student at Eastern Illinois University. Your participation in this research project is completely voluntary and you may withdraw at any point with no penalty.

You have been asked to participate in this study because you are a facilitator of a celiac disease support group in one of nine Midwestern states. Additional members of your support group are encouraged to participate and you are encouraged to forward this email on to other members of your support group. All members willing to participate will be included. No age or gender specifications have been established. Parents or legal guardians of children with celiac disease may help their child complete the survey if desired by providing access to the electronic survey via the link below. By providing access to the electronic survey and helping the child complete the survey, the parent or legal guardian is giving informed consent for the minor (17 years old or younger).

If you choose to participate, you will have until Tuesday, June 15, 2010 to complete the survey via kwiksurveys.com. The survey will take approximately 15 minutes or less to complete. To complete the survey, please follow the link at the end of this email and fill out the questions to the best of your ability. By clicking finish survey at the end, you will submit the survey.

Completing the survey electronically presents no foreseeable risk. There is no anticipated discomfort or negative outcomes associated with completing the survey.

The data collected by this research project will help health practitioners better understand educational techniques for dietary instruction for celiac disease individuals. By taking a moment to complete the survey, you will be contributing to the understanding of celiac disease and the challenges individuals face with the gluten-free diet. All responses to the survey will be confidential and anonymous.

Please contact Jill Barnes at jlbarnes@eiu.edu or Dr. Karla Kennedy-Hagan at kjkennedyhagan@eiu.edu for any additional information, questions, or concerns.

If you wish to participate, please click on the link below. By clicking the link below, you are giving your consent to participate in the study.
Link:

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Appendix B

Survey

Celiac Disease and the Gluten Free Diet

This research project is designed to examine factors related to Celiac Disease and the gluten-free diet. A gluten-free diet is a diet free from wheat, barley, or rye.

Instructions: Please answer each question to the best of your ability.

Definition of Key words: Compliance: To conform to the guidelines; an act of following a prescribed treatment

Non-Compliance: Not following a prescribed treatment

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1. What is the name of the state where you live?
2. What is your gender?
3. What is your current age?
4. What was your age at the time of diagnosis of Celiac Disease?
5. Rate your current knowledge of the gluten-free diet on a scale of 1 to 10, with 1 being not knowledgeable and 10 being always knowledgeable.

   1 2 3 4 5 6 7 8 9 10

   Never Always

6. Rate your current compliance with the gluten-free diet on a scale of 1 to 10, with 1 being never compliant and 10 being always compliant.

   1 2 3 4 5 6 7 8 9 10

   Never Always

7. Rate the availability of gluten-free products where you live on a scale of 1 to 10, with 1 being never available and 10 being always available.

   1 2 3 4 5 6 7 8 9 10

   Never Always

8. Rate how influential social pressures are to your decision to comply with the gluten-free diet on a scale of 1 to 10, with 1 being never influential and 10 being always influential.

1	2	3	4	5	6	7	8	9	10
Never									Always

9. Rate the severity of your physical symptoms related to celiac disease on a scale of 1 to 10, with 1 being never severe and 10 being always severe.

1	2	3	4	5	6	7	8	9	10
Never									Always

10. Rate how expensive you find gluten-free foods to be in comparison to the gluten-containing counterparts on a scale of 1 to 10, with 1 being not expensive and 10 being very expensive.

1	2	3	4	5	6	7	8	9	10
Never									Always

11. Rate how influential cost of gluten-free foods is you're your decision to comply with the gluten-free diet on a scale of 1 to 10, with 1 being never influential and 10 being always influential.

1	2	3	4	5	6	7	8	9	10
Never									Always

12. Do you wish to share any experiences you've had will eating a gluten-free diet? If so, please discuss below.